

AMENDED IN SENATE MARCH 27, 2012

**SENATE BILL**

**No. 1267**

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**Introduced by Senator Padilla**

February 23, 2012

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~~An act to amend Sections 105280 and 109910 of the Health and Safety Code, relating to public health. An act to add Chapter 2.6 (commencing with Section 56.18) to Part 2.6 of Division 1 of the Civil Code, relating to genetic information.~~

LEGISLATIVE COUNSEL'S DIGEST

SB 1267, as amended, Padilla. ~~Public health.~~ *Genetic Information Privacy Act.*

*Existing law prohibits discrimination on the basis of genetic information under various provisions of law, including, among others, the Unruh Civil Rights Act and the California Fair Employment and Housing Act. Existing law prohibits discrimination in the enrollment of health insurance plans on the basis of an individual's genetic characteristics, as defined. Existing law also imposes prohibitions on the disclosure by a health care service plan of the results of a test for a genetic characteristic contained in an applicant's or enrollee's medical records.*

*This bill would establish the Genetic Information Privacy Act, which would provide that an individual's genetic information, as defined, is protected by the right of privacy. The bill would, notwithstanding any other law, prohibit any person, as defined, from obtaining, analyzing, or disclosing genetic information without the written authorization of the individual to whom the information pertains, as specified, and would establish civil and criminal penalties for a violation of this prohibition, as specified. However, this bill would exempt from these prohibitions*

*and penalties law enforcement officials in the execution of their official duties, hospitals, laboratories, and physicians carrying out court-ordered tests, licensed health care professionals in medical emergencies, coroners and medical examiners in the execution of their official duties, any screening of newborn infants required by state or federal law, and disaggregated and anonymized data, as defined, that was either collected before the bill's enactment or if written consent is obtained. By creating new crimes, the bill would impose a state-mandated local program.*

*The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.*

*This bill would provide that no reimbursement is required by this act because it creates new crimes.*

~~Existing law requires the State Department of Public Health to administer various public health programs, including the childhood lead poisoning prevention program and the food safety inspection program.~~

~~This bill would make technical, nonsubstantive changes to these provisions.~~

Vote: majority. Appropriation: no. Fiscal committee: ~~no~~-yes.  
State-mandated local program: ~~no~~-yes.

*The people of the State of California do enact as follows:*

1     SECTION 1. Chapter 2.6 (commencing with Section 56.18) is  
2     added to Part 2.6 of Division 1 of the Civil Code, to read:

3  
4                     CHAPTER 2.6. GENETIC PRIVACY

5  
6     56.18. (a) This chapter shall be known, and may be cited, as  
7     the Genetic Information Privacy Act.

8     (b) For purposes of this chapter, the following definitions apply:

9     (1) "Anonymized" means data from which an individual's  
10    identifying information has been removed.

11    (2) "DNA sample" means any human biological specimen that  
12    is obtained or retained for the purpose of extracting and analyzing  
13    DNA to perform a genetic test.

14    (3) "Genetic characteristic" includes a gene, chromosome, or  
15    alteration thereof that may be tested to determine the existence or

1 risk of a disease, disorder, trait, propensity, or syndrome, or to  
2 identify an individual or a blood relative.

3 (4) “Genetic information” means, with respect to an individual,  
4 information about the genetic tests of the individual, the genetic  
5 tests of the individual’s family members, and the manifestation of  
6 a disease or disorder in family members of the individual. The  
7 term includes a request for, or receipt of, genetic services, or  
8 participation in clinical research that includes genetic services,  
9 by the individual or a family member of the individual.

10 (5) “Genetic service” means a genetic test, genetic education,  
11 or genetic counseling, including obtaining, interpreting, or  
12 assessing genetic information.

13 (6) “Genetic test” means a test for determining the presence  
14 or absence of genetic characteristics in an individual or the  
15 individual’s blood relatives, including tests of nucleic acids such  
16 as DNA, RNA, and mitochondrial DNA, chromosomes, or proteins  
17 in order to diagnose or determine a genetic characteristic.

18 (7) “Person” means an individual, partnership, corporation,  
19 association, business, business trust, or legal representative of an  
20 organization.

21 56.19. (a) Genetic information is protected by the right of  
22 privacy, and, notwithstanding subdivision (c) of Section 56.10, or  
23 any other law, shall not be obtained, analyzed, retained, or  
24 disclosed without the written authorization of the individual  
25 pursuant to subdivision (g).

26 (b) Any person who negligently violates subdivision (a) shall  
27 be assessed a civil penalty in an amount not to exceed one thousand  
28 dollars (\$1,000) plus court costs, as determined by the court, which  
29 penalty and costs shall be paid to the individual to whom the  
30 genetic information pertains.

31 (c) Any person who willfully violates subdivision (a) shall be  
32 assessed a civil penalty in an amount not less than one thousand  
33 dollars (\$1,000) and not more than five thousand dollars (\$5,000)  
34 plus court costs, as determined by the court, which penalty and  
35 costs shall be paid to the individual to whom the genetic  
36 information pertains.

37 (d) Any person who willfully or negligently violates subdivision  
38 (a) and the violation results in economic, bodily, or emotional  
39 harm to the individual to whom the genetic information pertains,

1 is guilty of a misdemeanor punishable by a fine not to exceed ten  
2 thousand dollars (\$10,000).

3 (e) In addition to the penalties listed in subdivisions (b) and (c),  
4 a person who commits an act described in subdivision (b) or (c)  
5 shall be liable to the person to whom the genetic information  
6 pertains for all actual damages, including damages for economic,  
7 bodily, or emotional harm which is proximately caused by the act.

8 (f) Each violation of this section is a separate and actionable  
9 offense.

10 (g) The written authorization required by this section shall  
11 satisfy all of the following requirements:

12 (1) Is written in plain language and is in a typeface no smaller  
13 than 14-point type.

14 (2) Is dated and signed by the individual or a person authorized  
15 to act on behalf of the individual.

16 (3) Specifies the types of persons authorized to obtain, analyze,  
17 or disclose genetic information about the individual.

18 (4) Specifies the nature of the genetic information authorized  
19 to be obtained, analyzed, or disclosed.

20 (5) States the name or functions of the persons or entities  
21 authorized to obtain, analyze, or receive the information.

22 (6) Specifies the purposes for which the information is collected.

23 (7) Specifies the length of time the authorization shall remain  
24 valid.

25 (8) Specifies whether the genetic information may be used for  
26 any commercial purpose.

27 (9) Specifies whether the genetic information shall remain  
28 identifiable or shall be made nonidentifiable.

29 (10) If the information is retained, specifies the manner in which  
30 the information shall be stored.

31 (11) Requires the destruction of the genetic information and  
32 sample after the specific purpose for which the consent was granted  
33 has been fulfilled.

34 (12) Permits the individual to limit access to the information to  
35 a certain person or persons.

36 (13) Permits the individual to revoke his or her consent in  
37 writing at any time.

38 (14) Advises the individual signing the authorization of the right  
39 to receive a copy of the authorization. Written authorization is  
40 required for each separate disclosure of the genetic information.

1     (h) *This section shall not apply to the following:*

2     (1) *A law enforcement official in the execution of his or her*  
3 *official duties.*

4     (2) *A hospital, laboratory, or physician carrying out*  
5 *court-ordered tests for genetic information.*

6     (3) *A licensed health care professional, as defined in Section*  
7 *56.05, in medical emergencies.*

8     (4) *A coroner or medical examiner in the execution of his or*  
9 *her official duties.*

10    (5) *Disaggregated and anonymized data that was collected*  
11 *before the enactment of the act adding this section.*

12    (6) *Any screening of newborn infants required by state or federal*  
13 *law.*

14    (7) *Disaggregated and anonymized data if written consent under*  
15 *subdivision (g) is obtained.*

16     SEC. 2. *No reimbursement is required by this act pursuant to*  
17 *Section 6 of Article XIII B of the California Constitution because*  
18 *the only costs that may be incurred by a local agency or school*  
19 *district will be incurred because this act creates a new crime or*  
20 *infraction, eliminates a crime or infraction, or changes the penalty*  
21 *for a crime or infraction, within the meaning of Section 17556 of*  
22 *the Government Code, or changes the definition of a crime within*  
23 *the meaning of Section 6 of Article XIII B of the California*  
24 *Constitution.*

25     ~~SECTION 1. Section 105280 of the Health and Safety Code~~  
26 ~~is amended to read:~~

27     ~~105280. For purposes of this chapter, the following definitions~~  
28 ~~apply:~~

29     ~~(a) “Appropriate case management” means health care referrals,~~  
30 ~~environmental assessments, and educational activities, performed~~  
31 ~~by the appropriate person, professional, or entity, necessary to~~  
32 ~~reduce a child’s exposure to lead and the consequences of the~~  
33 ~~exposure, as determined by the United States Centers for Disease~~  
34 ~~Control, or as determined by the department pursuant to Section~~  
35 ~~105300.~~

36     ~~(b) “Lead poisoning” means the disease present when the~~  
37 ~~concentration of lead in whole venous blood reaches or exceeds~~  
38 ~~levels constituting a health risk, as specified in the most recent~~  
39 ~~United States Centers for Disease Control guidelines for lead~~  
40 ~~poisoning as determined by the department, or when the~~

1 concentration of lead in whole venous blood reaches or exceeds  
2 levels constituting a health risk as determined by the department  
3 pursuant to Section 105300.

4 (e) “Department” means the State Department of Public Health.

5 (d) “Health assessment” has the same meaning as prescribed in  
6 Section 6800 of Title 17 of the California Code of Regulations.

7 (e) “Screen” means the medical procedure by which the  
8 concentration of lead in whole venous blood is measured.

9 (f) “Health care” means the identification, through evaluation  
10 and screening, if indicated, of lead poisoning, as well as any  
11 followup medical treatment necessary to reduce the elevated blood  
12 lead levels.

13 (g) “Environmental lead contamination” means the persistent  
14 presence of lead in the environment, in quantifiable amounts, that  
15 results in ongoing and chronic exposure to children.

16 SEC. 2. Section 109910 of the Health and Safety Code is  
17 amended to read:

18 109910. “Department” means the State Department of Public  
19 Health.